Medical Futility and the Critically Ill Patient

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Abstract

Today, the world of critical care medicine has given us the capabilities to accomplish things that were only dreamed of a few decades ago. When combined with the increasing importance of patient autonomy and economics in healthcare, these new capabilities have caused conflicts about what is too little, and what is too much. Medical futility becomes an issue whenever these conflicts arise. Understanding how to deal with issues surrounding futility begins with defining it. A firm definition is not possible or desirable, but revolves around the probability of being able to achieve a patient's goal with modern medicine. Establishing this understanding between the patient and their family (team), and the healthcare team, is dependent on trust between the two. It must be recognized that there are many reasons for families to not trust healthcare professionals and that these reasons need to be explored and dealt with. Sometimes conflicts regarding predictions and economics need to be addressed. Once trust is established a goal for a course of medical treatment should be discussed from the patient's perspective. This discussion should involve the physician's best judgement as to the chances of achieving this goal, and what type of discomfort or indignity, if any, the patient may experience. Only after these have been clearly discussed can decisions regarding medical futility be made. To date, the U.S. Courts have refused to grant physicians and hospitals the power to override the opinions of family members on matters of futility. However, with time, a consensus of public opinion should influence decisions regarding medical futility.

Introduction

The role of the physician has always been to help the sick and injured. Foremost to this has been the desire to cure or mend the patient in order to return them to functional health. Today, an equally important part of caring for patients is helping them die with dignity and without suffering when they cannot be cured or mended. Nowhere is this dual role more important than in the modern Intensive Care Unit (ICU). Here the physician has at his disposal knowledge, machines, and monitors which can in many cases sustain physiologic life almost indefinitely. For the critical care physician the determination of when care is 'worthwhile' and when it becomes 'medically futile' becomes a constant struggle that takes place not only within the context of the individual's own values and ethics, but also with those of the patient and their family. This struggle is illustrated by the estimate that 90% of patients (compared with 51% in 1988) who die in ICUs do so after a decision has been made to withdraw or withhold life support, making it the most common cause of death in the ICU.[1]

More recently, society has had to face the reality that medical resources are not unlimited and that some mechanism for distributing these resources must be found. This has added to the equation the issue of economics and led to the new bad word for the next century, "managed care." Thus, medical futility is a term that has incited a whole host of discussions bringing together conflicts regarding autonomy, paternalism, trust, primacy of life, quality of life, healthcare reform, and medical rationing. It is a concept that, when taken literally, applies to very few cases, but when interpreted broadly and within the context of the imprecision of medicine, is frequently invoked. We will not solve the debate over medical futility, rather we will discuss its issues so as to help the participant understand the concepts and be prepared to help themselves, other healthcare professionals, and, most importantly, patients and families, deal with it when it arises.

Attempting to Define Medical Futility

Historically, physicians made decisions based upon the basic principles of beneficence (do good) and nonmalefience (do not inflict intentional harm).[2] These issues were usually discussed and decided among the physicians and information was disclosed selectively in order to maintain control over what they felt was best for the patient. This allowed them to withhold care that was felt to be of no benefit. In the words of Hippocrates, to not provide interventions to those "overmastered by their diseases."[3] Perhaps as a backlash to this paternalism, ethics and the law today give primacy to the principle of autonomy. Patients can refuse any intervention, even life saving ones. However, today's practitioners often interpret this as meaning that they must also offer every available treatment, no matter how absurd or overzealous, and that they must allow patients and families to decide when treatment is futile. Health care reform and the debates of today have begun to elevate the importance of distributive justice in medical ethics.[2] This is the idea that all of society should have an equal distribution of medical resources. The Single Master View illustrates the concern that this concept brings about, stating that health care providers "should not be providers and rationers of health care simultaneously."[4]

Throughout history the concept of futility has been imprecise. If discussed among a group of individuals, terms such as not going to work, impossible, very unlikely, wasted effort, and useless are typical of what might be used. The word futility is derived from the Latin *futilis*, which means one that pours or melts. Greek mythology holds that the daughters of King Argos, having killed their husbands,

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were condemned by the God Hades, to collect water for eternity using leaky sieves.[5] Oxford Dictionary interprets this as an action that is "leaky, hence untrustworthy, vain, failing of the desired end through intrinsic defect."[6] Random House Dictionary calls it "incapable of producing any result; ineffective, useless, not successful."[7] In a medical sense, a futile action is one that is unable to achieve the desired goal or result.[8]

Hippocrates called on clinicians to acknowledge when their efforts would probably fail, stating, "whenever...a man suffers from an ill which is too strong for the means at the disposal of medicine, he surely must not even expect that it can be overcome by medicine....to attempt such futile treatment is to display an ignorance which is allied to madness." Hippocratic teaching further indicates that it is improper for a physician to engage in a practice that is hopeless, or that causes more burden than benefit.[3]

At the patient's bedside medical futility becomes an issue when families (or physicians) demand care that to others seems to be unreasonable. This care can leave care givers feeling frustrated, cause pain and suffering for patients and families, and waste precious resources. Sometimes this can be the result of denial, a lack of understanding or trust, or personal beliefs.

A Goal Oriented approach to determining medical futility has been advocated by Younger.[9] He believes that determining that an action is futile must be based upon identification of a "goal." Next, it must be determined if the goal is attainable. Finally, it must be considered whether the goal is worth achieving and at what cost. Examples of possible goals in medicine are:[10]

1. Physiologic - Will a mechanical ventilator adequately oxygenate a patient?
2. Postponing Death - Will a mechanical ventilator postpone death?
3. Improving the Quality or the Duration of Life - Will mechanically ventilating the patient allow him or her to eventually live independently?

The Society of Critical Care Medicine has taken a similar position, although narrower. In May 1997, it defined futility as actions that "will not accomplish their intended goal." They cited four categories of treatment; treatments with no physiologic benefit, those extremely unlikely to be of benefit, those that have some beneficial effect, but are extremely costly, and those of uncertain or controversial benefit. Only the first category would be futile, and thus futility should be invoked only rarely, and should usually not be disputed.[8]

The U.S. Department of Veteran's Affairs has stated that "futile treatment may be defined as that which affords no benefit, or marginal benefit, weighing intrusiveness, burden, and risk against the ultimate outcome." This approach is broader and considers both the risk and burden with outcome. Rather than defining futility the VA sought to give examples of futility, such as treatment that would only prolong suffering or the dying process, patients that have no hope of leaving the Intensive Care Unit, treatments that have supportive data of poor outcome or provides only physiologic benefit without hope of attaining the patient's goals.[11]

In Hawaii, the St. Francis Healthcare System has stated that futility needs to be addressed on a case-by-case basis, but should be considered whenever "treatment options have little or no chance of providing benefit." They give examples of this including treatments that only prolong the dying process or patient suffering, maintain a persistent vegetative state, will not end permanent dependence on intensive care, do not improve the quality of life, or where there is no data to indicate a likelihood of a successful outcome.[12]

An alternative approach to determining medical futility is Probability Oriented. According to this approach a treatment should be considered medically futile if one of two categories are met. The "quantitative" category of futility occurs when an intervention has been useless in the last 100 cases. Statistically, this would give the clinician 95% confidence that no more than 3 successes would occur in each 100 trials. The "qualitative" category of futility is when any treatment merely preserves a permanent state of unconsciousness or fails to end a total dependence on intensive medical care. This treatment should be regarded as nonbeneficial and, therefore, futile." Such treatment should not be offered and, if demanded, should not be given.[13] This approach has been criticized, in part, because of the unlikelihood that any one practitioner will have attempted a treatment on 100 occasions.[14,15]

A more recent concept in futility has been the Futility Gap. This gap is defined as the distance between the highest level of functioning achievable by medical care and the lowest quality of life acceptable to the patient.[16]

Although most experts seem to base definitions of futility upon a goal oriented approach, a practical working definition probably lies somewhere between this and the others. Caplan summed it up by stating that, "medical futility must be understood as referring to both the probability and the desirability of attaining a...goal."[17] Futility can be thought of as the final standard for terminating care when the patient's own wishes cannot be determined.

Where is the Trust?

Today, the most common mode of death in the ICU is the withdrawal or withholding of life support.[18] This decision is usually based upon the physician's assessment of a poor prognosis. Ninety percent of families agree, within five days, to a physician's recommendation to limit life support, and only 4% refuse such recommendations altogether.[1] Thus the majority of patients and families are willing to place significant trust in their physicians when it comes to matters of life or death.

Recently, however, in forums ranging from the U.S. Congress to Hollywood and the Academy Awards, restricted access to proper healthcare has begun to make patients wary of healthcare organizations and physicians, and has begun to erode the traditional trust that the public has placed in its doctors. This places even greater responsibility on the physician when patients or families disagree or are hesitant to follow their recommendations concerning futile care. Personal values of physicians can easily cloud decisions of medical futility.[19] Studies have found that clinicians themselves differ about what constitutes *quality of life*. Wachter found that despite the same statistical prognosis, physicians were more willing to write DNR orders for patients with a diagnosis of AIDS or cancer, than liver or heart disease.[20] An article by Curtis indicates that non-whites had more DNR orders than whites, despite the same diagnosis and prognosis.[21] Thus the danger of having physicians give guidance in these matters is that the guidance may be more opinion than medical judgement and are thus subject to abuse. Trust can play a significant role in a patient's or family's response to a physician's decisions.

Trust can also be put into question by the principle of Effect

Versus Benefit.[13] In a patient has suffered a massive stroke that has left her in a vegetative state, intubation and mechanical ventilation will have the *effect* of maintaining oxygenation to the patient's organs, but it will not produce the *benefit* of restoring the patient to conscious life. Is this treatment futile? Most people would feel that this is futile, but some people might believe in the ultimate importance of biological life and disagree.[13] Can there be trust when the values of patients differ fundamentally from those of the care givers? Veatch has stated, "life-prolonging care is fundamental....How offensive it must be to a patient who believes in the ultimate value of biological life to be prohibited access to life-prolonging care by one's clinician."[22] When trust is lost the difficulties grow. Families often begin to pit one member of the healthcare team against another. They seek out inconsistencies in statements feeling that pointing these out to the providers will force them to give better care.[16]

The best way to avoid these situations is to establish trust and understanding through communication. Communication must be established early and be honest and open. Preferably this is done in the office or pre-morbid setting where the stress is minimal and the patient's interests can be protected beforehand.[23]

Can Medical Futility Be Predicted?

The use of withdrawing and withholding of life support prior to a patient's death has grown dramatically throughout the 1990s. In general, this determination is being done by physicians based upon their knowledge of diseases, the particular patient, and their own experience or judgement. However, the reliability of these physician determinations has come increasingly into question. Today, there are multiple severity of illness models that provide an estimate of a patient's hospital mortality. Some of the more widely tested models include the Acute Physiology and Chronic Health Evaluation (APACHE),[24] Mortality Prediction Model (MPM),[25] Simplified Acute Physiology Score (SAPS),[26] and the Pediatric Risk of Mortality (PRISM).[27] Recently, the Potentially Ineffective Care (PIC) model has attempted to predict combined outcomes of high resource utilization and short survival.[28] Many of these, in particular APACHE and SUPPORT, have established very large databases from which they have cross-validated and tested models to predict survival chances. These models have become indispensable as a point of reference for comparing outcomes between divergent ICUs and for stratifying populations based upon severity of illness for critical care research.

Can these models be used to predict individual outcomes and thus, medical futility? The current answer to this question is no. First, the concepts of probability and confidence intervals are very difficult to understand for most practitioners, let alone patients and their families. The predictions are often reported in a wide range of times and percentages. For example, during a retrospective review, the SUPPORT database predicted that an individual had a 17% chance of surviving for 2 months on the day before the patient actually died. It likewise gave the patient a 51% chance of 2 month survival 1 week before actual death.[29] Review of data from APACHE showed similar, although slightly more pessimistic, results.[29] In addition, the severity of illness models, by their nature, do not factor in data about patient preferences and goals, and individual experiences. Despite these constraints, attempts to develop databases of sufficient power to be able to predict futility continue. Teres has stated that "with the increasing size of various databases there may soon be enough patients to reach quantative estimates, as suggested by Schiderman, et. al."[30]

Today, severity of illness models, while potentially helpful in guiding a physician, cannot be used as a sole guide for determining medical futility.

The Role of Managed Care in Medical Futility

Controlling the spiraling costs of healthcare has become a major priority in the United States. The recognition of limited resources and the promise of unlimited medical capabilities has led to the development of Health Maintenance Organizations (HMO) in an attempt to control costs, while continuing to provide state-of-the-art care. This has especially reached into the ICU, where cost and technology clash daily with medical futility. It has been estimated that up to 28% of all acute hospital costs come from the ICU, so it would seem to be the logical place to practice cost containment.[31] More recently, a backlash against HMOs has derived from the perception that they are cutting costs and making money at the expense of patients and their healthcare. Highly influential public mediums such as the movies, newspapers, television, and even the U.S. Congress and the President, have sent a message that when it comes to health, an HMO cannot be trusted. As a part of HMOs physicians are often seen as their allies. The medical literature may contribute to this impression by suggesting that HMO practices are able to reduce the utilization of medical resources, such as critical care, by restricting PIC at the end of life.[32] One study found that $10,000 per patient and 0.5% of all ICU admissions could be saved by earlier use of DNR orders.[33] Another stated that there are three circumstances where requested interventions can be refused: when the care is unlikely to be of benefit, when the intervention is likely to cause more harm than good, and when the intervention conflicts with the principle of distributive justice.[34]

Others have addressed the issue from a different perspective stating, "we could not afford a universal health system based on patient's demands. Such systems...allocate health care to socially powerful people...to the disadvantage of those with less power..."[35] It has been suggested that the issue of allocating resources to critically ill patients should revolve around distributive justice.[2] This concept has been further refined, by some, as referring only to those individuals that have certain moral or social value. How this will eventually be defined and how this principle will eventually be applied to critical care remains to be seen. Traditionally, during busy times when resources are scarce, the average severity of illness or acuity increases in ICUs.[36] Today, politics and economics can play a role in deciding who should be in an ICU.[37] This has led to widespread concern that the poor or minorities will receive disproportionately low levels of care.[38] Until firm guidelines are established, critical care physicians need to be alert to the restriction of resources based on questionable concepts.

To accomplish all of the above fairly, HMOs need to dedicate appropriate resources for care, guidelines for distributing the resources (preferably based upon established practice guidelines), appeal mechanisms, and monitoring systems. All of this should be done in conjunction with physicians, administrators, and patients, in an open atmosphere. Individual cases should be complimented by

patient preferences and directives.[39] Finally, although profit is important, maximizing medical benefit should remain the priority. Without such an approach the system will risk deteriorating into something worse than when it started.

Establishing a Goal

Establishing a practical and working definition of medical futility is a highly difficult and emotionally charged issue. In most cases, the concept of futility is unnecessary because the patient's family and physicians quickly come to agreement about how to care for the patient. When there are conflicts, however, they are strongly felt by both the healthcare team and the family. Because of the often differing perspectives of the parties involved, what may be futile to one group may be beneficial to another. Values can become presented as futility. Thus a firm broadly applicable definition is probably not possible or advisable. As we have seen, some authors and organizations have felt that most issues revolving around futility can be resolved by the establishment of a *goal*. Focusing on the goal and then the possible interventions is probably the best approach. For various reasons, most clinicians interact with families using an *intervention-oriented* approach. However, the best way to establish a goal is a *goal-oriented* approach.

Two scenarios will help to illustrate the difference between an intervention-oriented and a goal-oriented approach. A 76 year old man has severe pneumonia on top of his end-stage lung disease. Prior to this he was limited in his activities, but interactive and enjoyed visiting with his family. His mental and respiratory status is deteriorating to the point that he may require mechanical ventilation.

Intervention-Oriented - The physician approaches the family and states, "your father is getting very sick. Do you want us to continue to do everything?" or "Do you want us to put him on a breathing machine?" This approach is very common and can be very stressful and misleading to a family. Most (not all) people want a cure for their loved one, something that will at least return them to a level equal or better than before their hospitalization.[9] When offered an intervention without discussing the chances of achieving this goal, many families will infer that the goal must be achievable or else it wouldn't be discussed.[9] Unrealistic goals can quickly develop. In addition, when offered without discussion, many families perceive a burden of deciding whether or not they should allow the death of their loved one without the knowledge of the chances of actually achieving a cure. This is not fair. Another intervention-oriented approach is to unilaterally not offer or refuse interventions that the family may desire, without helping them understand the unpleasant realities or the ability of the intervention to achieve the goal.[9]

Goal-Oriented - The physician sits down with the family and explains why their father has begun to deteriorate. He focuses the discussion on the present situation. A discussion ensues about what outcome (goal) they believe their father would desire if he were able to participate. It may be revealed that he had a living will or that he had voiced an opinion to a family member. Possible goals may be: a fully independent life, life where he can interact with his family, life at home, or, in some cases, biological existence at all costs. Patients and families are more inclined to request futile interventions when they do not have adequate information about diagnosis and prognosis.[9] The levels of medical uncertainty or mistrust of the physician may become evident and can be dealt with. Once a goal is established a decision on an intervention must still be based on the probability of success weighed against the quality of the outcome. Low probability can be balance by high value or utility. Different interventions impose different amounts of pain, suffering and indignity on the patient and family. A patient may want a certain goal, but only be willing to put up with a certain amount to achieve it. Thus a conclusion to a goal may be transfer to the intensive care unit, intubation and mechanical ventilation for a period of time, to see if the patient recovers. Or it can be to forego intubation altogether and to allow the patient to die peacefully. Or it can be full care at all costs, with eventual transfer to a full care facility. It is important to realize that differences in these matters may not be about futility, but rather about *values or goals.*

The Courts and Futility

The cases of *Karen Ann Quinlan (1976)* and *Claire Conroy (1985)*, both in New Jersey, and *Barber (1983)*, in California, established the rights of families and patients to refuse or withdraw care, even if that care was life sustaining or saving.[40] Of interest is the decisions by the courts pertaining to the right of physicians to refuse interventions demanded by a patient or family.

United States Courts have so far refused to grant physicians and hospitals the power to override the opinions and desires of family members when they desire continuing life support, especially if the patient is not overtly suffering. They have yet to address the specific issue of medical futility. *Baby L (1990)* was a 2 year old girl with severe neurologic disabilities who required repeated hospitalizations for uncontrolled seizures and recurrent aspiration pneumonias. The physicians sought to withhold further aggressive interventions, but the mother insisted. Before the issue could be decided by the courts another facility was found that was willing to care for the patient.[41] *Helga Wanglie (1991)* was a 85 year old woman who was ventilator dependent in a persistent vegetative-state. After they were unable to obtain the agreement of the family to withdraw support, the hospital asked the courts to appoint a conservator on the grounds that such care was futile because it was not beneficial (not physiologically futile). The husband cross-filed, requesting that he be the appointed conservator. The court then appointed the husband as the conservator. However, before the issue of whether or not health professionals could override a family's wishes was further discussed, Mrs. Wanglie died. Observers have noted that the court agreed with the husband by appointing him as the conservator, citing this as evidence that the court supported the principle that who was making a decision was more important than what the decision was.[42] The key here was not so much futility, but goals. *Baby K (1992)* was born anencephalic and required repeated hospitalizations for mechanical ventilation. No other hospital would take the child, so the Virginia hospital turned to the courts and requested that they not be required to provide mechanical ventilation to the child, citing a Virginia statute that states physicians are not required to "prescribe or render medical treatment" that is "medically or ethically inappropriate." Eventually the courts sided with the mother, citing a federal law requiring hospitals and practioners to provide emergency care when requested. Notably, they avoided the issue of whether or not patients with futile conditions should be provided with supportive care.[9]

Societal consensus or opinion plays an important role in how

courts interpret the "public interest." While it is recognized that most people look at a permanent state of unconsciousness as an undignified existence, the courts have refused to state that this opinion is absolute. This legal posture may begin to change over time. Public opinion polls have consistently revealed that the majority of Americans do not believe that patients in a persistent vegetative state should receive unlimited life sustaining interventions. Although it is of physiologic benefit, such interventions are not capable of returning the patient to interactive life. On the basis of persistent public opinion on the issue, standards for withdrawing futile care in these circumstances can be developed that will be supported by the courts. Already it has been suggested that patients in a vegetative state should be assumed to not want life prolonging support unless evidence exists to the contrary.[43] Economic constraints may also influence judicial decisions. In 1995, a Massachusetts jury acquitted the physicians of Catherine Gilgunn (a 72 year old woman who had suffered irreversible brain damage) of malpractice for entering a Do Not Resuscitate order on her, shortly after which she subsequently died. One of the patient's daughters had adamantly opposed this step, despite agreement with the physicians by the patient's other two daughters. The patient's husband had refused to intervene. The court stated that "the State's interest in pursuing life is high when human life can be saved..., but wanes when the afflictions are incurable." It further stated that we must "balance her (the patient's) preference against the medical judgement to withdraw such treatment in the context of not whether, but for how long and at what cost, her life might be extended."[16] Thus a consensus regarding healthcare goals for society may influence the definition of futility.

Discussion

Today, the world of critical care medicine has given us the capabilities to accomplish things that were only dreamed of a few decades ago. When combined with the increasing importance of patient autonomy and economics in healthcare, these new capabilities have caused conflicts about what is too little, and what is too much. Medical futility becomes an issue whenever these conflicts arise. Understanding how to deal with issues surrounding futility begins with defining it. A firm definition is not possible or desirable, but revolves around the probability of being able to achieve a patient's goal with modern medicine. Establishing this understanding between the patient and their family (team), and the healthcare team, is dependent on trust between the two. It must be recognized that there are many reasons for families to not trust healthcare professionals and that these reasons need to be explored and dealt with. Sometimes conflicts regarding predictions and economics need to be addressed. Once trust is established a goal for a course of medical treatment should be discussed from the patient's perspective. This discussion should involve the physician's best judgement as to the chances of achieving this goal, and what type of discomfort or indignity, if any, the patient may experience. Only after these have been clearly discussed can decisions regarding medical futility be made. To date, the U.S. Courts have refused to grant physicians and hospitals the power to override the opinions of family members on matters of futility. However, with time, a consensus of public opinion should influence decisions regarding medical futility.

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